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Association

NVA News

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Vulvodynia's Psychological Impact on the Partner

By David C. Foster, MD, MPH, and Merrill B. Kotok, BSN, RNC

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Vulvodynia-afflicted women commonly suffer from significant psychosocial problems including sexual dysfunction, anxiety, infertility, and the breakup of sexual and marital relationships.[1-3] The sexual consequences of vulvodynia lead to unique psychosexual stress for both individuals in a relationship. Although much has been written about the psychological impact of vulvodynia on affected women, its impact on the pain-free partner has not been a focus of discussion.

At present, we are nearing completion of an NIH-funded, randomized clinical trial for treatment of localized vulvodynia, or vulvar vestibulitis. During the five years of our clinical trial we have had the opportunity to meet with many partners of vulvodynia-afflicted women, both heterosexual and homosexual, and observe their individual responses to the problem. We encourage partners' participation and allot ample time for couples' visits. The emotional effects of dyspareunia, or painful sexual intercourse, can result in a significant interpersonal struggle for many couples and affect acceptance and adherence to therapy. Skepticism toward the medical treatment of vulvodynia is often magnified by the pain-free partner's exposure to an earlier clinical opinion that his or her partner's pain is "in her head." Vulvodynia involves both medical and psychological dimensions that are closely intertwined and essentially inseparable. Most practices managing these types of vulvar problems characterize vulvodynia as a pain condition with psychological overlay, rather than a psychological condition with pain overlay.

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The Many Faces of Vestibular Pain

By Andrew Goldstein, MD, FACOG

Dr. Goldstein is the director of the Centers for Vulvovaginal Disorders in Washington, DC, New York City and Annapolis, Maryland. He is also an instructor in the division of gynecologic specialties in the department of obstetrics and gynecology at Johns Hopkins School of Medicine.

A few years ago, I had an important conversation with Gordon Davis, MD, one of the world's leading vulvar specialists, which caused me to re-think the way I diagnosis and treat women with Vulvar Vestibulitis Syndrome (VVS). Prior to that conversation, I knew that recent research indicated that the pain of VVS might be caused by an overgrowth of nerve endings in the vestibular mucosa. I was also aware of an increasing amount of evidence that pelvic floor muscle rehabilitation provided relief for some patients with vestibular pain. I was very pleased to have this additional treatment option for my patients, but became more and more confused. Why would physical therapy work if there are too

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Pain-free sexual partners exhibit common behavioral patterns when confronted with a rejection of intimacy. Pain-free partner responses may, at times, be the product of the particular time of pain onset in their partner. In other words, a pain-free partner may respond to *primary* versus *secondary* vulvodynia in different ways. The problem of *primary* vulvodynia, i.e., pain upon first attempt at sexual intercourse, may naturally select out partners who are more supportive and understanding, particularly if the problem is recognized early in the relationship. On the other hand, *secondary* vulvodynia may result in a more difficult adjustment for the pain-free partner, because of the prior mutual experience of "normal" pain-free sexual activity. The reaction to vulvodynia by the pain-free partner often reflects common psychological responses, including stress/anxiety, depression, guilt, anger and a sense of loss. (*Please note that the listed responses below are not intended to reflect a progression or hierarchical pattern.*)

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Stress/anxiety—Even though stress and anxiety are ever-present and familiar to all, they can vary in both degree and outward manifestation in the woman with vulvodynia and her pain-free partner. Both may experience stress and anxiety because of the multiple doctors' appointments, the failure of empiric therapies, the repeatedly invasive and painful pelvic exams, the loss of control of one's own (or the partner's) body, the concern about surgery and the inability to conceive. Over time, this state of heightened stress and anxiety will inevitably sap energy from both members of the couple, reduce the zeal to enjoy life and further lead to depression.

Depression—Clinicians have recognized that depression often coexists with pain in vulvodynia patients. The pain-free partner, however, also can experience depression exacerbated by his or her partner's condition, and this situation is often overlooked in treating couples. Pain-free partners may become more involved with work, lose sleep, increase substance abuse or exhibit significant changes in weight. Based on a combined sense of powerlessness and depression, the pain-free partner may retreat from meaningful interaction with both the affected partner and others. Such reclusive tendencies in the pain-free partner may leave the false impression of lack of caring or concern in the eyes of the vulvodynia-afflicted woman.

Guilt—The pain-free partner often feels responsible for the problem in the first place, given that sexual intercourse is often the heralding event. A guilt response in the pain-free partner can lead to fear of intimacy, loss of libido and erectile dysfunction. Other times, the partner may show an overly doting and excessively protective behavior in an attempt to prevent or reduce pain in their partner.

Loss—The sense of loss in the pain-free partner can manifest itself in many ways including loss of intimacy, loss of sexual spontaneity, loss of a sense of status or prestige (in the eyes of others), loss of self-esteem, loss of control, and occasionally an actual loss of health, such as an exacerbation of asthma or hypertension.

Anger—Vulvodynia patients are often times misdiagnosed[4], left untreated, fail to respond to empiric therapies, or fail to undergo surgery that might correct the problem. Not surprisingly, such experiences lead to anger in both the patient and pain-free partner. A

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partner's anger can be heightened by the failure to engage in "normal" sexual activity that is excessively promoted by today's media. Anger can be manifested in a number of ways, including: hostility to clinical staff, sexual or physical abuse upon the afflicted partner and motivation to pursue sexual activity outside of the established relationship.

Interventions by the Practitioner

Both patients and pain-free partners appreciate knowing early in therapy that their psychological reactions to the complications of vulvodynia are experienced by many affected couples. Treating clinicians need to be very cognizant of the psychosexual dimension of vulvodynia and develop therapeutic regimens that encourage sexual partner participation rather than ignore it. With permission from the patient, participation of the pain-free partner at the medical visit should be welcomed. At times, particularly in heterosexual relationships, the gynecologic visit may be the first ever experienced and a brief discussion of the physical exam format can reduce anxiety. Why some pain-free partners attend the gynecologic visit and others do not remains little understood at this time. Certainly, the reasons for partner presence or absence are multifactorial. If the vulvodynia-afflicted member of the couple consents, therapeutic intervention may include having the partner attend the gynecologic exam, receive professional instruction about normal anatomy and be shown the anatomic localization of their partner's genital pain.

Couples counseling can sometimes be as simple as the doctor or therapist giving permission to try sexual intercourse. Couples education may also include the recommendation of particular sexual positions that might reduce pain and application techniques of topical analgesics and lubricants prior to intercourse. Couples education can also facilitate a discussion of the broader psychosexual and spiritual toll of vulvodynia. A review of the history of the couple's sexual activity, both before the onset of pain and before the recognition of vulvodynia as a diagnosis, can help to guide recommendations for sexual and intimacy patterns during and following successful treatment. Practitioners also need to recognize at an early stage of therapy which couples may benefit from additional professional intervention such as family-centered therapy or sexual counseling. The indication for referral is often self-evident based on a need for greater intervention time than is commonly available, or a need for therapy that requires special expertise.

Personal Interventions by the Couple

Couples have to develop skills for coping with the complex physical and psychosexual aspects of vulvodynia. Both participants need to understand and take responsibility for their own feelings and also take time to understand how dyspareunia affects their partner. Both should strive to understand differences in coping mechanisms between themselves and their partners. They should reduce interpersonal isolation by maintaining intimacy at multiple levels and become knowledgeable about what is sexually pleasurable versus painful for the other. Couples might consider setting up specific "date-nights," times when they are free from other responsibilities such as family, child care or work. Finally, couples should strive to nurture their relationship by taking ample time off together and maintaining realistic expectations. Even the most effective treatment regimens for vulvodynia will require adherence to these regimens for extended time periods. Patience and interpersonal support are key to a successful outcome.

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Vestibular Pain

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many nerve endings? Who gets which treatment? Should women try them all?

My conversation with Dr. Davis challenged me to expand my thinking about the causes of vestibular pain, and then it hit me: vestibular pain should not be regarded as a single entity. What I finally understood is that vestibular pain (just like chest pain, foot pain or any other pain) has multiple causes. If a person went to the doctor with a pain in her foot, we would expect the doctor to determine if the patient's foot pain is caused by a broken bone, an infection, or too-tight shoes. We would certainly expect the doctor to take an x-ray before putting a cast on the foot, and we would feel very uneasy if the doctor couldn't find the cause of the pain and instead shrugged and called it "footodynia."

So what is my point? Over the past few years, I have diagnosed at least a dozen diseases or conditions that can cause the symptoms associated with VVS, i.e., vestibular pain and redness, and pain during sexual intercourse. While many of these disorders appear very similar, subtle differences, combined with a woman's history, can distinguish the source of the pain and lead to a logical treatment path. *The existence of multiple causes might explain why no single treatment works for all women with vestibular pain.* Below I have compiled a list of the most common conditions and their treatment.

Vulvar Atrophy

To remain healthy, vestibular tissue needs adequate levels of both estrogen and testosterone, which are often altered by certain medications or conditions. Vulvar atrophy is often caused by oral contraceptive pills, surgical removal of the ovaries, chemotherapy for breast cancer, hormonal treatment of endometriosis and simply menopause. The distinctive features are that symptoms occur gradually and the entire vestibule is affected. There are low levels of estrogen, free testosterone and elevated sex-hormone binding globulin levels in the patient's blood work. The first-line treatment is the application of topical estrogen or a compounded topical estrogen/testosterone cream or gel.

For my patients with vulvar atrophy who have been taking an oral contraceptive, I strongly recommend stopping the pill and then prescribe a compounded estrogen/testosterone gel. It is not sufficient to simply stop taking the oral contraceptive *or* use the hormonal gel. Both components are necessary to resolve the symptoms. In my opinion, every woman who has vestibular pain that began while taking an oral contraceptive should stop taking the pill and use estrogen/testosterone gel as a first-line treatment.

Pelvic floor dysfunction (levator ani syndrome)

In this condition, the muscles that surround the vestibule are tight and tender. This muscular tightness can cause tenderness and redness of the vestibule, without the existence of an intrinsic problem of the vestibular tissue. Often the posterior portion of the vestibule (near the perineum) is affected more than the anterior part (near the urethra). Pelvic floor dysfunction can be detected by a thorough exam of the levator ani muscles. Treatments include intravaginal physical therapy, muscle relaxants such as Valium, biofeedback, and most recently Botox, which is used to augment the physical therapy.

Vaginitis

Sometimes inflammation in the vagina is so severe that the inflammatory white blood cells pour out of the vagina and coat the vestibule, causing vestibular pain. There are two categories of vaginitis: infectious and sterile (non-infectious). Infectious vaginitis represents approximately 90 percent of all cases of vaginitis in women of reproductive age. It is often caused by organisms such as yeast or trichomonas. Yeast vaginitis is treated with an antifungal and sometimes diet recommendations, while trichomonas is treated with the antibiotic metronidazole.

Sterile or non-infectious vaginitis can be caused by exposure to chemicals in vaginal creams, spermicides and lubricants, as well as latex condoms. In addition, sterile vaginitis can be attributed to

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NVA Continues to Award Record Number of Grants

In December 2006, NVA's Executive Director made a special appeal to several longtime donors to help fund a research proposal by Steven Witkin, PhD, professor of immunology and director of the division of immunology and infectious diseases in the department of obstetrics and gynecology, Weill Medical College of Cornell University. Because of our donors' generous response, this past January the NVA awarded a grant to Dr. Witkin, one of the most dedicated and prolific researchers studying the etiology of Vulvar Vestibulitis Syndrome (VVS). Since 2000, Dr. Witkin has conducted numerous studies showing that some women with VVS exhibit polymorphisms (genetic variations) that make them more susceptible to developing the condition. His research demonstrates that women with VVS are more likely to exhibit a reduced capacity to 'turn-off' inflammation (IL-1ra gene polymorphism), an increased capacity to initiate inflammation (IL-1beta gene polymorphism) and a reduced capacity to combat Candida albicans infections (MBL gene polymorphism).

It has been difficult for researchers to identify the precise etiology of VVS, because women with the condition report a variety of events that initially trigger their symptoms, including vulvovaginal infection, childbirth, hormonal alteration and chemical and laser treatment. Dr. Witkin's recent proposal stated that, *regardless of the initial trigger*, VVS may be due to vestibular peripheral nerve damage caused by prolonged exposure to *reactive oxygen species* (ROS). These oxygen-containing molecules can be induced by a number of infectious or non-infectious insults and can damage nerve cells. Specifically, he suggests that ROS persistence, which increases susceptibility to nerve damage and maximizes regional sensitivity, may be the result of genetic variations that either reduce the ability to directly inactivate ROS or foster a prolongation of ROS production.

With the NVA grant, Dr. Witkin is comparing the DNA of VVS patients whose symptoms began after a specific event such as childbirth or vulvovaginal infection, to that of patients whose symptoms were not associated with an identifiable trigger. In addition, he will examine blood samples from both subgroups to measure their immune response to the yeast and hyphal forms of Candida. In summary, Dr. Witkin is seeking evidence of a unifying mechanism that would explain how VVS can result from multiple causes. The existence of a unifying mechanism would lead to (i) an improved ability to identify women at risk for developing VVS, (ii) the testing of potentially effective preventative strategies and (iii) the formulation of novel treatments.

In February 2007, NVA awarded a grant to Bernard Harlow, PhD**,** Mayo professor and division head, department of epidemiology and community health, University of Minnesota School of Public Health. In 2000, Dr. Harlow was the recipient of a five-year NIH grant to study the prevalence of vulvodynia and identify risk factors for developing the disorder. Among his key findings are that a large percentage of women who develop vulvodynia report severe pain and difficulty with first tampon use, and that some women who develop VVS exhibit an easily triggered pro-inflammatory immune response. Harlow hypothesizes that, in some women, vulvodynia is the consequence of a genetic predisposition that leads to an altered immuno-inflammatory response that may occur before the onset of menustration.

With his recent NVA grant, Harlow examined vulvar tissue specimens from women with vulvodynia for specific altered immuno-inflammatory response markers. These tissue specimens, obtained under his earlier NIH-funded research, were analyzed for the presence of neurogenic proinflammatory mediators, cytokines and bactericidal proteins. Harlow's current laboratory findings, combined with his prior epidemiological data, will be submitted in a grant application to the NIH later this year.

NVA Funds New Vulvodynia Clinics

In May 2006, the NVA created the Dr. Stanley C. Marinoff Vulvodynia Career Development Award to encourage interested faculty to pursue clinical or academic work in the vulvodynia field. The award provides seed money for pilot research, writing a medical article on vulvodynia or the creation of a vulvar pain clinic. One of the 2006 recipients of the Career Development Award was Gina Anderson, MD, assistant professor of obstetrics, gynecology and women's health at the New Jersey Medical School. Dr. Anderson used her grant to establish a vulvar pain clinic in Newark, New Jersey, a previously underserved community. Because lack of access to vulvodynia experts is a major problem experienced by many

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Research

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vulvar pain patients, the NVA Board decided to allocate funding from our general operating budget toward the development of two additional vulvar pain clinics, one in Washington, DC, and another in Grand Blanc, Michigan.

Mary Kendell, MS, WHCNP, adjunct assistant professor of obstetrics and gynecology, George Washington University School of Medicine, Washington, DC, was awarded a grant to develop a curriculum to train and evaluate ob/gyn residents in the treatment of women with chronic vulvar pain. The educational component of the curriculum includes both print and web-based learning tools, as well as practical training of medical residents in standardized exam techniques and vulvar colposcopy. To promote and evaluate medical residents' competency, the George Washington University School of Medicine utilizes a state-of-the-art standardized patient testing center that allows its students and residents to hone their skills. In this controlled environment, faculty can observe and record resident/patient interactions and provide real time feedback to residents on their patient care, medical knowledge, interpersonal skills, professionalism and systems based practice. Ms. Kendell's initial goal is to develop a successful standardized curriculum that will improve medical residents' competence and level of comfort in evaluating and treating chronic vulvar pain disorders. Her ultimate goal is to establish a vulvodynia clinic at George Washington University School of Medicine.

Theodore Fellenbaum, MD, assistant program chair of obstetrics and gynecology, Genesys Regional Medical Center in Grand Blanc, Michigan, was awarded a grant to organize a community-based vulvodynia clinic that also promotes resident physician education. The Genesys Medical Center demonstrated its commitment to establishing this clinic by matching the amount of NVA's grant. Dr. Fellenbaum is collaborating with members of the Genesys obstetric & gynecologic residency program and the Genesys medical education department. The goals of this collaboration are to: (i) screen, diagnose and treat genital pain disorders of unknown etiology; (ii) provide previously unavailable training in genital pain for Genesys and other hospital ob/gyn resident physicians and medical students; (iii) provide lectures on vulvodynia to other medical disciplines; and (iv) establish a means for ongoing academic research on vulvodynia.

NVA would like to fund the opening of at least one new vulvodynia clinic each year. If you are a health care provider interested in starting a clinic, please contact Chris Veasley at chris@nva.org. If you would like to make a donation to help us establish vulvodynia clinics, please contact Gigi Brecheen at gigi@nva.org or 301-949-5114, or mail a check to NVA, PO Box 4491, Silver Spring, MD 20914. Thank you. ■

Help Women with Vulvodynia

Private donations play a critical role in helping NVA staff and volunteers fulfill our mission. These donations enable us to create valuable resources for women suffering from vulvodynia, improve our support network, organize campaigns to increase federal research funding, open vulvar clinics and award pilot research grants. Over the past 10 years, NVA has awarded more than $200,000 in research grants, enabling many recipients to obtain substantial, long-term NIH funding.

Ways you can give:

- **Credit Card Donation** on NVA's secure website, www.nva.org.
- **Monthly Giving –** If you bank online, you can set up an automatic monthly donation.
- **Workplace Giving** – Some employers will match all or part of a charitable contribution. Check with your employer's human resources or benefits office. You may also be able to give through payroll deductions.
- **Honor an Occasion** – If you make a gift in honor of a birthday or anniversary, NVA will acknowledge the gift to both you and the honoree. You may also choose to make a gift in honor or in memory of a loved one.
- **Online Shopping** – Before visiting Amazon.com, go to our home page, www.nva.org, and click on the Amazon link. NVA will receive 5% of your total purchase amount.
- **Appreciated Securities Donation** – You will receive a tax benefit by making a gift of appreciated securities. Contact Chris Veasley at chris @nva.org or 401-398-0830 for more information.
- **Bequest** – To help ensure that our services continue in the future, please consider making a charitable bequest to the NVA in your will. ■

NVA Campaigns for Increased Research Funding

During the third week of April 2007, thousands of NVA supporters throughout the US and Canada participated in our third annual Grassroots Research Advocacy Campaign. The campaign's goal is to increase vulvodynia awareness and lobby our nation's legislators for increased government funding of vulvodynia research.

On Capitol Hill, NVA Director of Research Chris Veasley met with key members of Congress serving on the health-related committees that oversee NIH appropriations. During the same week, women with vulvodynia and their family members met with or sent e-mails to their Senators and Representatives urging an increase in vulvodynia research funding. NVA supporters met with legislators in 15 states, including more than half of the senators serving on the Health Appropriations Subcommittee, as well as the first female Speaker of the House, Representative Nancy Pelosi (D-CA). In addition, 2,500 letters were sent to more than 400 Congressional members. NVA's Canadian constituents wrote letters to their provinces' Health Ministers, explaining how the condition impacts their lives. Crystal Suitor, a dedicated volunteer and support leader from Calgary, Alberta, led the Canadian arm of the campaign. She wrote a heartfelt, compelling letter to Alberta's Health Minister. (*See sidebar.*)

NVA's Chris Veasley spent several days on Capitol Hill meeting with legislators serving on health-related committees, including the chair and ranking member of the Senate Health Appropriations Subcommittee, Senators Tom Harkin (D-IA) and Arlen Specter (R-PA), respectively, and the ranking member of the Senate Health, Education, Labor and Pensions Committee, Senator Michael Enzi (R-WY). She also met with the co-chair of the House of Representatives' Women's Caucus, Representative Lois Capps (D-CA), and both co-chairs of the Task Force on Women's Health within the Caucus, Representatives Tammy Baldwin (D-WI) and Cathy McMorris-Rodgers (R-WA).

Several key issues were addressed at these meetings. NVA highlighted that, since 2003, funding of the NIH has failed to keep pace with the increasing cost of biomedical research, and in absolute terms, the value of NIH grants has eroded. Simply put, a grant that might have paid for $100,000 of research costs in 2003 only buys $88,000 worth in 2007. In addition, Chris pointed out that the number of applications submitted to NIH has increased dramatically during the past four years, whereas budget restraints have forced NIH to limit funding to

Canadian Support Leader Urges Research Funding

Dear Health Minister,

After graduating from high school, my dreams of college and travel soon ended when I started experiencing chronic vulvar pain. I had severe pain when walking, sitting or even wearing pants. The symptoms were debilitating. After three years of seeking help, and six doctors later, I was finally diagnosed with vulvodynia. I spent the next three years trying a combination of treatments with minimal results. I got to the point where I had exhausted available treatments and was told that I would be living the rest of my life in chronic pain. At the age of 23, it was a devastating thing to hear. Although I had much to be thankful for in my life, I wondered if I would I ever travel, get married and have a family. I wanted to get up in the morning and not have to worry if it was too cold outside to wear a skirt, because wearing pants would be too painful.

I knew I had to be persistent and keep searching and researching. I contemplated surgery and eventually went outside Canada to have a vestibulectomy, a surgery with relatively high success rates. Now it is one year later and I can sit and walk without pain! I am in a wonderful strong relationship that has grown throughout this hardship. I continue to do as much as I can to help other women who suffer from vulvodynia and feel that I survived this difficult experience for a purpose. I am urging you to promote funding of vulvodynia research through the Canadian Institutes of Health Research, so that all women with vulvodynia can receive the quality of treatment that everyone in chronic pain deserves.

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Advocacy

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only the top 15 percent of applicants. Consequently, NIH turns away many deserving scientists who struggle to secure funding elsewhere so they can reapply to NIH. Facing this situation, some scientists at the beginning of their careers decide to abandon research altogether.

NVA proposed that, to help remedy this situation, legislators should support at least a 6.7 percent increase in NIH funding in FY2008. We also advocated similar increases in 2009 and 2010, which would restore the purchasing power lost to NIH since 2003 and sustain our country's investment in biomedical research. In addition, NVA promoted the inclusion of stronger language on vulvodynia in the FY2008 Appropriations bill, directing NIH to allocate funds to support vulvodynia research. Finally, we asked legislators to co-sponsor or vote in favor of the *National Pain Care Policy Act of 2007* when it is introduced in the US House and Senate later this year. Although the bill isn't vulvodynia-specific, it does address the larger umbrella issue of neglected and under-treated chronic pain conditions. Specifically, the Act would authorize an Institute of Medicine conference on pain, permanently establish an NIH Pain Consortium and focus national attention on the need for pain management.

In FY2006, Congress directed NIH to collaborate with NVA to develop and implement a national campaign to (i) raise the public's awareness of vulvodynia, (ii) provide resources for women suffering from the disorder and (iii) educate the medical community about the condition. After her Capitol Hill meetings, Chris was joined by Peter Reinecke, legislative advisor to NVA (and formerly Senator Harkin's chief of staff), to discuss the upcoming NIH vulvodynia awareness campaign with Vivian Pinn, MD, Director of the Office of Research on Women's Health, and several other NIH representatives. Dr. Pinn, a long-time champion of women's health, has been very supportive of NVA's goals for many years and is playing a key role in the planning of the NIH vulvodynia campaign to be launched later this year.

NVA's final advocacy week meeting was with Louis DePaolo, MD, Chief of the Reproductive Sciences Branch, National Institute of Child Health and Human Development (NICHD), to discuss the current status of vulvodynia research funding in the institute. NICHD is one of 27 institutes and centers at the NIH and vulvodynia research is funded primarily through this institute. Although NICHD has spent approximately $1 million annually for vulvodynia research over the past seven years (a small amount by NIH standards), *there has not been any increase in the annual level of funding.* Several factors contribute to this funding freeze, including the increase in the overall number of applications submitted to NIH and continuing NIH budget cutbacks in recent years. We voiced our concern about the stagnant funding level and stressed the importance of ensuring that appropriate reviewers, i.e., scientists and clinicians knowledgeable about vulvodynia, are on the committees that score vulvodynia research applications. Dr. DePaolo invited a continuing, open dialogue with NVA and promised to work with his staff to find the best way to promote research efforts in the field.

The NVA greatly appreciates the efforts of those who volunteered their time to meet with, or write to, their elected officials. The participation of individuals across the US and Canada in this grassroots advocacy effort is critical to our future success. ■

L to R: NVA's Erin DeLury Lawrence, Kathy Harrison and Marjorie Veiga, after their meeting with Rep. Frank R. Wolf (R-VA)

Volunteers Take Center Stage in Publicity Efforts

The best seller, "The Tipping Point," describes three types of people that are instrumental in promoting cultural change: persuaders, connectors, and mavens, i.e., those who collect and share information. NVA volunteers Cindy Harrington, Lisa Ellin and Pam Fischer, RN, possess many of the characteristics exhibited by these types of leaders and, fortunately, they have applied their skills to increasing public awareness of vulvodynia.

Last fall, Cindy Harrison, a vulvodynia patient from Philadelphia, wrote and delivered a letter to radio talk show host Dr. Dan Gottlieb during one of his public appearances. In her letter, she related the challenges faced by a woman suffering from an often misdiagnosed and misunderstood condition. "I knew sharing my story would help me heal and empower others. I believed I could remove the stigma of having vulvodynia by saying my name and telling my story," said Cindy. Her letter convinced Dr. Gottlieb to include vulvodynia on one of his shows about women's health. "As a listener, I knew him to be loving and compassionate - so I trusted he would treat my story with respect and empathy." Within weeks, she was interviewed for the segment on his "Voices in the Family" public radio program. The other guests included Deborah Kotz, health editor of U.S. News & World Report, and Phyllis Greenberger, President and CEO of the Society for Women's Health Research. On the program, "Dr. Dan" and his guests discussed issues ranging from gender bias in medical research to vulvodynia. During her allotted time, Cindy educated listeners about vulvodynia and offered a message of hope to those who suffer from this chronic pain. Cindy doesn't have medical training or influential connections, but she ventured out of her comfort zone to effect change. Subsequently, she committed to helping NVA convince the editors of U.S. News & World Report and other popular publications to feature stories on vulvodynia.

Lisa Ellin, NVA's former support group leader in southern New Jersey, is also a connector and persuader. She gathered contact information on dozens of media outlets in her area and approached them, both in writing and with follow-up phone calls, to request that vulvodynia be brought to the attention of their audience. "You've got to be bold and willing to share deeply," said Lisa. "If we do what we've always done (remain silent), we'll get what we've always gotten, which is lack of coverage in the media," she added. In 2005, Lisa and her husband appeared on the TV program *The Art of Women's Health* with NIH-funded vulvodynia researcher Gloria Bachmann, MD, director of the Women's Health Institute and chief of the Ob/Gyn service at Robert Wood Johnson University Hospital, UMDNJ-New Brunswick. In January 2007, she was again interviewed on *Seeking Solutions with Suzanne*, a program that aired on CNN Headline News on Cox Cable TV systems. "I was nervous at first, but then I felt like I was sitting in Suzanne's living room, chatting comfortably," Lisa remarked. Lisa recently moved to the Washington, DC area and we are confident that she will continue to be a proactive voice for women with vulvodynia.

In summer 2006, our outstanding Chicago-area support leader of the past nine years, Pam Fischer, RN, was featured in an article on vulvodynia in the American Academy of Pain Management's magazine, *The Pain Practitioner*. In the article, titled *A Very Private Pain,* Pam discussed both the physical and emotional pain of vulvodynia. She also described the rewards and sense of accomplishment she derives from serving as a resource person for other women with vulvodynia. Several hundred Chicago-area vulvodynia sufferers have benefitted from Pam's dedication to her volunteer work.

The NVA wishes to express our sincere appreciation to Pam, Cindy and Lisa for sharing their personal stories and for their commitment to empowering other women with vulvodynia. NVA would like to acknowledge more of our volunteers who demonstrate initiative in facilitating publicity or are exemplary support leaders. If you or someone you know has participated in this type of effort (regardless of the size of the audience), please let us know. Alternately, if you have an interesting or creative idea for generating publicity in newspapers, magazines, or on a radio or TV show, please submit your idea to NVA via our website, www.nva.org. (Click on *Help Raise Awareness*).

Personal Letters

Sometimes publicity opportunities arise suddenly and NVA has to be prepared to submit to the media women's personal stories on coping with vulvodynia, as well as the names of expert physicians and researchers. This year, NVA co-founder and publicity director, Marjorie MacArthur Veiga, sent an e-mail to

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Publicity

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hundreds of NVA supporters asking them to send us letters or e-mails describing their personal experience living with vulvodynia. What follows are two of the inspirational and heartfelt personal stories we received:

My journey started when I was 51 years old; it took me four years to gain understanding and control of my vestibulitis, vulvodynia and vaginismus. Those years I "felt" my vulvar area every waking moment—a prickling, burning, smarting, stinging pain—like catching a pubic hair on a zipper. I had sex with my husband of 25 years only a couple of times during these years because of the vulvar pain. On reflection, I had pain during intercourse much of my sexual life, but it had now intensified to a point I could not have my husband touch me. I couldn't wear underwear because of the pain—how could I have sex? My husband has been kind, patient, never forceful, and definitely by my side during this journey.

This condition took over more than our sex life; it became the focus of our relationship. I knew we were consumed by this condition when he walked in from work and said: "7 or 8?" referring to the pain scale I used to rate my pain. He didn't even say "hi." He saw me and immediately he saw my pain. I was depressed, in chronic pain, and felt alone.

I was ambitious in my search for help. Over the years, I went to four gyns, a vulvar specialist, an allergist, a nutritionist, a dermatologist, a chiropractor, and an acupuncturist. I was prescribed numerous treatments. Some were slightly helpful, some initially helped but not for long, some were totally ineffective, and some actually made the condition worse. One day I saw a TV advertisement for a pelvic floor physical therapist and impulsively called. With her expertise, I have found help and hope; much of the time I now feel "normal" and relatively pain-free. It has taken two and one-half years of physical therapy, but I feel like I've regained control. I have my life back and my husband has his wife back. I am forever thankful for the skill and expertise of my physical therapist and hope that many others will benefit from this type of treatment.

Dianne L. Clemens
Age 57

When I was married in October 2004, I had never been sexually active. Then, on my wedding night, I learned just how painful sex was going to be for me. I spent my wedding night and entire honeymoon in tears because sex was so painful. When my husband and I returned from our honeymoon, I made an appointment with an Ob/Gyn. I remember sobbing and squeezing my husband's hand while lying on the exam table. First the doctor wanted to treat my problem as an infection, so I tried a few different medications. My husband and I were not having sex and I felt inadequate. I continued seeing the doctor once a week for a few weeks before he referred me to a specialized surgeon in the southeastern US. The specialist recommended a vestibulectomy and I underwent the surgery in March 2005, five months after my wedding. After my surgery, I couldn't work for six weeks and was prescribed pelvic rest for three months. I couldn't walk, sit or do any normal activities. Finally, after three months, the doctor tested me and there was no pain or discomfort! I was amazed that there was no pain and remember asking him, "Wouldn't that have hurt three months ago?" My doctor replied, "That was the same exam that made you cry three months ago."

Now my husband and I are able to enjoy a normal, pain-free sex life. It was difficult, however, to resume a sex life right after my pelvic rest ended. We had trained ourselves not to be sexually attracted to each other for eight months, and all of a sudden, everything was fine and sex didn't hurt. I appreciate that I have such a supportive husband and this experience has definitely made our relationship much stronger. Since we were not able to have sex, we had to communicate in many other ways that made us closer.

I am very grateful there are resources for people like me, who have never even heard about vulvodynia. I am thankful every day for the doctor who diagnosed me and the surgeon who performed my vestibulectomy. As an unexpected bonus, I was hired as a medical assistant to the doctor who diagnosed me, because I had become friends with the office staff.

Lauren Hughes
Age 26

Vestibular Pain

(from page 4)

lack of estrogen (*See vulvar atrophy above*) or a condition known as Desquamative Inflammatory Vaginitis (DIV). This condition is characterized by copious yellowish discharge and the cause is unknown. Although DIV is difficult to “cure,” often it can be treated with a combination of intravaginal steroids, the antibiotic Clindamycin and topical estrogen.

Vulvar Dermatoses

Several different dermatologic conditions of the vulva can cause vestibular pain. The most common condition, affecting approximately one percent of all women, is Lichen Sclerosus. The second most common is erosive Lichen Planus. Both Lichen Sclerosus (LS) and Lichen Planus (LP) are chronic, autoimmune inflammatory conditions, most commonly affecting the skin of the vulva. Both conditions are characterized by pain during sex, as well as intense vulvar itching, burning, pain, tearing, decreased clitoral sensation and changes of the vulvar anatomy. Since the early 1990s, the mainstay of treatment for LS has been clobetasol (Temovate), an ultra-potent topical corticosteroid. Unfortunately, LS is typically much more difficult to control. While the ultra-potent corticosteroids such as clobetasol, (and more recently the macrolide immunosuppressants) are the first-line treatment for LP, it is often necessary to use systemic immunosuppressants such as prednisone or Methotrexate if the condition is advanced. (*See* Dermatologic Diseases of the Vulva *in* NVA News, *Summer 2006*.)

Irritant or Allergic Contact Dermatitis

Unfortunately, most women expose their vulvas to dozens of different chemicals almost every day. Even the gentlest soap may contain many different chemicals in the form of perfumes, dyes and preservatives. All toilet paper, sanitary pads and tampons contain chemicals. Laundry detergents and fabric softeners used to wash underwear and towels add to this chemical burden. A woman may be sensitive or allergic to any one of these chemicals, which can cause inflammation and pain in the vestibule. The solution is to identify and eliminate the source of the allergic or irritant reaction. In general, it is prudent to wash the vulva with water only, use scent-free detergent and other relatively chemical-free products.

Many women with vestibular pain have been unnecessarily subjected to many courses of antibiotics and antifungals by well-intentioned health care providers. Some vulvovaginal experts think that repeated exposure to anti-fungals often leads to an irritant or allergic contact dermatitis and possibly to Vulvar Vestibulitis Syndrome (VVS).

Vulvar Vestibulitis Syndrome

After ruling out the above conditions, one is left with the diagnosis of VVS, or vestibulodynia. Recent medical research has shown that there is neuronal proliferation, or increased density of nerve endings, in the vestibular mucosa of women with VVS. The two main subgroups of VVS are *primary* and *secondary*. Women with *primary VVS* experience pain from their first attempt at sexual intercourse and women with *secondary VVS* initially experience pain-free intercourse, but then subsequently acquire the condition.

There is compelling evidence that *primary VVS* is a congenital problem or birth defect. S*econdary VVS,* occurring after a period of pain-free intercourse, can be triggered by multiple events, such as an allergic reaction to vaginal creams, vulvovaginal infection and several other possibilities. Treatments for *secondary VVS* include, but are not limited to, tricyclic antidepressants, lidocaine, capsaicin, and surgical removal of the affected tissue, e.g., vulvar vestibulectomy with vaginal advancement. Many vulvar specialists disagree, but in my opinion, *primary VVS* can only be cured with vestibulectomy.

Conclusion

In closing, it is imperative that a woman experiencing chronic vestibular pain undergo a thorough evaluation by a vulvovaginal expert familiar with all of the above conditions. To increase the likelihood of a successful outcome, it is essential that treatment of vestibular pain be individualized and directed at a specific cause. ■

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I WANT TO SUPPORT THE NVA AND RECEIVE MORE INFORMATION ON VULVODYNIA.

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The NVA needs the support of everyone: patients, families, and health care providers.

☐**$45** ☐**$60** ☐**$100** ☐**Other $** ___________

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☐**Yes, I would like to be contacted by other NVA supporters in my area.**

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Please send your check or money order, payable to NVA, together with your name, address and telephone number to: NVA, P.O. Box 4491, Silver Spring, Md. 20914-4491.

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